

**AMENDED CHARTER****CENTER FOR INHERITED DISEASE RESEARCH ACCESS COMMITTEE****PURPOSE**

The **Secretary of Health and Human Services (Secretary)** is mandated under Section 301 of the Public Health Service (PHS) Act, as amended (42 U.S.C. 241), to support through grants, cooperative agreements, and contracts, research studies and related activities in the health fields. This includes research relating to human genome research, which is expressly authorized under Section 485B of the PHS Act, as amended (42 U.S.C. 287c), establishing the National Center for Human Genome Research, subsequently renamed the National Human Genome Research Institute (NHGRI). In addition, the Secretary is authorized under Section 487 of the PHS Act, as amended (42 U.S.C. 288), to support research and research training through National Research Service Awards.

The Center for Inherited Disease Research (CIDR) is a consortium of Institutes and Centers of the National Institutes of Health (NIH) and has as its main objective the identification of the genetic loci and allelic variants that play important roles in abnormal development, physiology, and behavior. CIDR will focus, in particular, on mapping loci responsible for the genetic contribution to common disorders in humans, including, but not limited to, cardiovascular and pulmonary disease, cancer, psychiatric disorders, diabetes, and autoimmune diseases. The NHGRI is the lead agency of the consortium which manages the CIDR through a Board of Governors representing each of the NIH institutes and centers. The Center for Inherited Disease Research Access Committee (Access Committee) shall advise the Board of Governors of CIDR regarding applications from investigators wishing to gain access to the genotyping and genetic analysis capabilities of CIDR.

**AUTHORITY**

42 U.S.C. 282(b)(6), Section 402(b)(6) of the PHS Act, as amended. The Access Committee is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees.

**FUNCTION**

The Access Committee shall advise the Director, NM, and the Board of Governors, CIDR, on the scientific and technical merit of applications seeking to use the resources and facilities of the CIDR. The primary assessment of the Access Committee is to determine whether or not the proposed "trait" can be mapped (using the genome-wide genotyping methods of CIDR) given the sampling strategy, sample size, and analytic methods. Under most circumstances the Access Committee will accept that the disease/trait phenotype will be appropriately characterized and that this component of the study, as well as the biological/medical importance of the disease/trait, will be evaluated by the Initial Review Group. Results of the Access Committee's review will be used by the Board of Governors in making decisions about the final scheduling of funded projects.

The members shall survey, as scientific leaders, the status of research and research training in their fields.

Rec'd 5/11/00  
CIDR # 5167

As necessary, the Access Committee and its subcommittees may call upon special consultants, assemble ad hoc working groups; and convene conferences, workshops, and other activities.

## **STRUCTURE**

The committee **shall** consist of 12 members, **including** the **Chair, appointed by** the Director, NIH, **from** **authorities knowledgeable in the various disciplines and fields of human** genetics, quantitative genetics, linkage and segregation analysis, and genotyping technology.

**Members shall be invited to serve for overlapping terms of up to four years; the term for a member who is to serve as Chair may include a fifth year.**

**As necessary, standing and ad hoc** subcommittees of the **Access Committee**, composed of members from the parent committee, may be established to perform specific functions within the Access Committee's jurisdiction. The Department Committee Management Officer shall be **notified** upon establishment of each **standing** subcommittee and shall be **provided information** on its **name**, membership, function, and estimated frequency of meetings.

The Chairs of each subcommittee may be designated as **Cochairs for the** Access Committee as a whole and upon approval by the **subcommittee** Chair, the advice of the subcommittee shall be considered the advice of the **Access Committee**.

A member of one subcommittee may serve as a voting member of other subcommittees when that member's expertise is required. However, that member shall **not** be counted in determining the presence of a quorum.

The permanent membership of the Access Committee may be supplemented at any meeting through temporary members who, because of their scientific expertise, are appointed to review some or all of the applications considered at that **meeting**. Notification to the prospective temporary member from the Designated **Federal** Official that the individual is to attend the meeting shall constitute a temporary appointment to the Access Committee for purposes of that **meeting**, and the individual shall have all the rights and obligations of committee membership at that meeting, including the right to vote on recommendations in which the individual fully participated as a reviewer. Temporary members will be included in the tracking of reviewers with respect to geographical distribution and ethnic and gender representation to ensure that appropriate balance of members' perspectives may be maintained. Temporary members shall not count toward a quorum.

A quorum for the conduct of business by the full Access Committee is seven members. A quorum for each subcommittee shall be five.

Management and support services shall be provided by Office of Scientific Review, NHGRI,

## **MEETINGS**

The full Access Committee shall meet in plenary session, as necessary, as called by the Chair with advance approval of a Government official, who shall approve the agenda. Meetings of the **Access Committee** and/or its subcommittees shall be held approximately three times per year at the call of the Chair, with the advance approval of a Government official who shall also approve the agenda. A Government official shall be present at all meetings of the Access Committee and of its subcommittees.

Meetings shall be open to the public unless determined otherwise by the Secretary; notice of all meetings shall be given to the public.

Meetings shall be conducted and records of the proceedings kept **as** required by applicable laws and Departmental policies.

#### COMPENSATION

Members shall be paid at the rate of \$200 per day, plus per diem and travel expenses, as **authorized** by Section 5703, Title 5 U.S.C, as amended, for persons in Government service employed intermittently. Members who are **full-time** officers or employees of the United States shall not receive compensation for service on the Access Committee.

#### ANNUAL COST ESTIMATE

The estimated annual cost for operating the Access Committee, including compensation and travel expenses for **members** but excluding staff support is \$35,464. The estimate of annual person-years of staff support required is 1.5, at an estimated annual cost of \$126,665.

#### REPORTS

In the event a portion of a meeting is closed to the public, a report shall be prepared which shall contain, as a minimum, a list of members and their business addresses, the committee's functions, dates, and places of **meetings**, and a summary of committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the **Department** Committee Management **Officer**.

#### ESTABLISHMENT DATE

April 30, 1997

#### TERMINATION DATE

Continuing.

Approved: ✓

Date

4/27/00

Acting Director, NIH

Ruth H. Kerocho Term

**CHARTER****CENTER FOR INHERITED DISEASE RESEARCH ACCESS REVIEW COMMITTEE****PURPOSE**

The Secretary of Health and Human Services (Secretary) is mandated under Section 301 of the Public Health Service (PHS) Act, as amended (42 U.S.C. 241), to support through grants, cooperative agreements, and **contracts**, research relating to human genome research. In addition, the Secretary is authorized under Section 487 of the PHS Act, as amended (42 U.S.C. 288), to support research and research training through National Research Service Awards.

The Center for Inherited Disease Research (CIDR) is a consortium of institutes and centers of the National Institutes of Health (NIH) and has as its main objective the identification of the genetic loci and allelic variants that play important roles in abnormal development, physiology, and behavior. CIDR will focus, in particular, on mapping loci responsible for the genetic contribution to common disorders in humans, including, but not limited to, cardiovascular and pulmonary disease, cancer, psychiatric disorders, diabetes, and autoimmune diseases. The National Center for Human Genome Research (NCHGR) is the lead agency of the consortium which manages the CIDR through a Board of Governors representing each of the eight institutes and centers. The Center for Inherited Disease Research Access Review Committee (Access Review Committee) will advise the Board of Governors of the CIDR regarding applications **from** investigators wishing to gain access to the genotyping and genetic analysis capabilities of the CIDR.

**AUTHORITY**

42 U.S.C. 282(b)(6), Section 402(b)(6) of the PHS Act, as amended. The Access Review Committee is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees.

**FUNCTION**

The Access Review Committee shall advise the Director, NIH, and the Board of Governors, CIDR, on the scientific and technical merit of applications seeking to **use the resources** and facilities of the CIDR. In formulating its advice, the Access Review Committee will utilize the recommendations based on initial scientific review of extramural research projects by the appropriate Initial Review Group (IRG) or of intramural research projects by the Scientific Director of the appropriate Intramural Research Program, and perform an analysis of each project for suitability, feasibility, impact on biomedical research, and priority of each application. The Access Review Committee will complete its examination of applications in a timely fashion in the interval between the initial review by the IRG and the appropriate council review. Results of the Access Review Committee's review will be used by the Board of Governors, CIDR, in making decisions about allocation of resources to the projects.

The members shall survey, as scientific leaders, the status of research and research training in their fields.

As necessary, the Access Review Committee and its subcommittees shall be able to call upon special consultants, assemble ad hoc working groups; and convene conferences, workshops, and other activities.

## STRUCTURE

Members, the Chair, and the Chairs of the subcommittees shall be selected by the Director, NIH, **from** authorities knowledgeable in the various disciplines and fields of human genetics, quantitative genetics, linkage and segregation analysis, and genotyping technology.

Members shall be invited to serve for overlapping terms of up to four years; the term for a member who is to **serve** as Chair may include a **fifth** year.

As necessary, standing and ad hoc subcommittees of the Access Review Committee, composed of members **from** the parent committee, may be established to perform specific functions within the Access Review Committee's jurisdiction. The Department Committee Management **Officer** shall be notified upon establishment of each standing subcommittee and shall be provided information on its name, membership, function, and estimated frequency of meetings.

The Chairs of each subcommittee may be designated as **Cochairs** for the Access Review Committee as a whole and upon approval by the subcommittee Chair, the advice of the subcommittee shall be considered the advice of the Access Review Committee.

A member of one subcommittee **may** serve as a voting member of other subcommittees when that member's expertise is required. However, that member shall not be counted in determining the presence of a quorum.

The permanent membership of the Access Review Committee may be supplemented at any meeting through temporary members who, because of their scientific expertise, are appointed to review some or all of the applications considered at that meeting. Notification to the prospective temporary member **from** the Designated Federal **Official** that the individual is to attend the meeting shall constitute a temporary appointment to the Access Review Committee for purposes of that meeting, and the individual shall have all the rights and obligations of committee membership at that meeting, including the right to vote on recommendations in which the individual fully participated as a reviewer. Temporary members will be included in the tracking of reviewers with respect to geographical distribution and ethnic and gender representation to ensure that appropriate balance of members' perspectives may be maintained. Temporary members shall not count toward a quorum.

A quorum for the conduct of business by the full Access Review Committee **is** seven members. A quorum for each subcommittee shall be five.

Management and support services shall be provided by **Office** of Scientific Review, NCHGR.

## MEETINGS

The full Access Review Committee shall meet in plenary session, as necessary, as called by the Chair with advance approval of a Government official, who shall approve the agenda. Meetings of the Access Review Committee or its subcommittees shall be held approximately three times per year at the call of the Chair, with the advance approval of a Government official who shall also approve the agenda. A Government **official** shall be present at all meetings of the Access Review Committee and of its subcommittees.

Meetings shall be open to the public unless determined otherwise by the Secretary; notice of all meetings shall be given to the public.

Meetings shall be conducted and records of the proceedings kept as required by applicable laws and Departmental policies.

#### COMPENSATION

Members shall be paid at the rate of \$150 per day, plus per diem and travel expenses in accordance with Standard Government Travel Regulations. Members who are **officers** or employees of the United States shall not receive compensation for service on the Access Review Committee.

#### ANNUAL COST ESTIMATE

The estimated annual cost for operating the Access Review Committee, including compensation and travel expenses for members but excluding staff support is \$106,568. The estimate of annual person-years of staff support required is 1.1, at an estimated annual cost of \$86,148.

#### REPORTS

In the event a portion of a meeting is closed to the public, a report shall be prepared which shall contain, as a minimum, a list of members and their business addresses, the Access Review Committee's **functions**, dates, and places of meetings, and a summary of the Access Review Committee's activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

#### ESTABLISHMENT DATE

#### TERMINATION DATE

Continuing.

Approved:

Jan 18, 1996  
Date

Harold Varnum  
Director, NIH